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Abstract

Background: Spiritual distress is prevalent in advanced disease, but often neglected, resulting in unnecessary suffering. Evidence to inform spiritual care practices in palliative care is limited.

Aim: To explore spiritual care needs, experiences, preferences and research priorities in an international sample of patients with life-limiting disease and family caregivers.

Design: Focus group study.

Setting/participants: Separate patient and caregiver focus groups were conducted at 11 sites in South Africa, Kenya, South Korea, the United States, Canada, the United Kingdom, Belgium, Finland and Poland. Discussions were transcribed, translated into English and analysed thematically.

Results: A total of 74 patients participated: median age 62 years; 53 had cancer; 48 were women. In total, 71 caregivers participated: median age 61 years; 56 were women. Two-thirds of participants were Christian. Five themes are described: patients' and caregivers' spiritual concerns, understanding of spirituality and its role in illness, views and experiences of spiritual care, preferences regarding spiritual care, and research priorities. Participants reported wide-ranging spiritual concerns spanning existential, psychological, religious and social domains. Spirituality supported coping, but could also result in framing illness as punishment. Participants emphasised the need for staff competence in spiritual care. Spiritual care was reportedly lacking, primarily due to staff members' de-prioritisation and lack of time. Patients' research priorities included understanding the qualities of human connectedness and fostering these skills in staff. Caregivers' priorities included staff training, assessment, studying impact, and caregiver's spiritual care needs.

Conclusion: To meet patient and caregiver preferences, healthcare providers should be able to address their spiritual concerns. Findings should inform patient- and caregiver-centred spiritual care provision, education and research.

Keywords

Spirituality, pastoral care, palliative care, religion and psychology, focus groups, qualitative research

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What is already known about the topic?

- Spiritual distress is prevalent among patients with advanced disease and is associated with poor quality of life and increased healthcare costs.
- An international survey of palliative care clinicians and researchers identified the need for research into the spiritual care needs, preferences and experiences of patients and their caregivers.
- However, the survey did not include patients and caregivers, whose research priorities in spiritual care remain unknown.

What this paper adds?

- Patients and caregivers in nine countries across four continents described many spiritual concerns, but reported spiritual care to be lacking.
- Participants' preferences highlighted the need for all interdisciplinary team members to address spiritual issues.
- Patients' and caregivers' research priorities included understanding the qualities of human connectedness, communicating sensitively about spirituality, staff education, spiritual care assessment, making spiritual care appropriate for diverse populations, studying the impact of spiritual care, and caregivers' spiritual care needs.

Implications for practice, theory or policy

- All staff caring for people with incurable, progressive disease should have a basic level of competency in spiritual care.
- Clinical education aimed at improving spiritual care should draw on the findings from this study regarding patient and caregiver needs, experiences and preferences regarding how spiritual care is provided.
- Identified research priorities can help ensure future spiritual care research is patient- and caregiver-centred.

Background

Through international consensus, spirituality has been defined as 'a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred'.¹ Spiritual distress is suffering related to this dimension of personhood and includes existential components (e.g. meaninglessness and hopelessness) as well as religious concerns. Spiritual distress is prevalent among patients with advanced disease^{2–4} and is associated with poor quality of life,⁵ end-of-life despair,⁶ requests for physician-assisted suicide⁷ and dissatisfaction with care.² Family caregivers report high levels of spiritual distress and unmet needs,^{8,9} particularly in the context of a life-limiting illness.^{10–12}

Spiritual care, that is, support from healthcare providers that aims to ameliorate spiritual distress, is neglected in clinical practice,^{2,13–18} with only 6%–28% of patients receiving spiritual care from their healthcare teams.^{2,5,19,20} This is contrary to patient wishes^{21,22} and policy guidance internationally.^{23–25} Evidence suggests that a lack of spiritual support by healthcare teams is associated with poor quality of life, dissatisfaction with care, less hospice utilisation, more aggressive treatment and increased costs, particularly among some ethnic minority groups and patients with high levels of religious coping.^{5,26–28} Spiritual care specialists such as chaplains (usually, and in the context of this study, a member of the clergy or religious leader) and pastoral care providers, who provide specialist spiritual support but may not be religious, possess advanced training in addressing spiritual concerns.

However, it is increasingly recognised that all healthcare providers working with patients with serious illness are responsible for providing basic spiritual care, referring to specialists when needed. Despite this, evidence to inform spiritual care provision and training is limited.^{29–33} A Northern and Western hemispheric bias is also evident, with most research conducted in the United States and Western Europe. To redress this deficit, an international evidence base is required to guide clinicians in the provision of spiritual care, to ensure patients' and family members' support needs are met.

Selman et al.³⁴ conducted an online survey via the European Association for Palliative Care (EAPC) to identify spiritual care research priorities among palliative care clinicians and researchers ($n = 971$), and found that understanding spiritual care needs and preferences in multi-faith, multi-cultural populations was a priority area. However, the survey did not consult patients and caregivers regarding their own research priorities in this domain, which is essential if the international research agenda is to be centred on service users' genuine needs.¹ The goal of this study was to explore patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care internationally.

Methods**Study design**

This is a qualitative focus group study, conducted in 2013–2014.

Box 1. Topic guide for patient focus groups.

Preamble: Usually medical care focuses on the physical dimension of health, like controlling pain and other symptoms, but in this discussion, our interest is focused on those aspects of illness that affect you as a person and might cause you to consider the deeper questions of life. In this study, we define questions relating to meaning, purpose and how we cope with difficult aspects of life as spiritual questions, but this might not be the word you use. Please use whatever language you want in this discussion.

1. In terms of your own illness experience, what are the deep questions you find yourself asking these days?
2. Would you describe any of these deep questions as spiritual? If so, why? If not, why not?
3. What does 'spirituality' mean to you?
4. What does 'spiritual care' mean to you?
5. Do you think spiritual care should be provided in healthcare? If so, why? If not, why not?
6. In the healthcare setting, what sort of people could best support you with any deep emotional or spiritual questions you have?
7. In your opinion, what should be the role of different people in providing spiritual support in healthcare? *Discuss each of nurse, doctor, GP, chaplain, social worker, psychologist, volunteer and community faith leaders. Prompts: How could these people best support you? Who should initiate discussions of spirituality in healthcare? Why?*
8. Based on your own understanding of spirituality, what in your experience are the most helpful things a healthcare provider can do if a patient has spiritual concerns? Can you share an example of a caregiving interaction where you felt your spirituality was addressed?
Prompts: If yes, by whom? (Were they from palliative care?) When in your illness? What happened? What worked well? If never experienced, why? (Prompts: staff time/interest, no one asked, did not want to, did not think appropriate to raise, etc.)
9. What are the least helpful things a healthcare professional can do if a patient has spiritual concerns? Can you share an example of a caregiving interaction in a clinical setting where your spirituality was not addressed or where you were adversely affected?
10. In your opinion as a patient, what are the most important areas of research to improve spiritual care? *Prompts: What do you think would really improve the quality of spiritual care or help to better meet your needs?*
11. Is there anything we did not talk about which you think it would be useful to know?

Participating sites

The study was conducted across 11 sites in nine countries: South Africa (Cape Town), Kenya (Nairobi), South Korea (Seoul), the United States (San Francisco, New York, Washington), Canada (Calgary), the United Kingdom (London), Belgium (Leuven), Finland (Tampere) and Poland (Poznan). All the sites provided care for patients with incurable, progressive disease, either through community or inpatient services, and had capacity to support the research. We aimed to recruit across a range of countries and regions to produce a broad, descriptive account of patients' and caregivers' needs, experiences, preferences and research priorities across diverse settings.

Sampling and recruitment

We aimed to recruit 4–12 participants per focus group, utilising purposive sampling to ensure diversity in diagnoses, age, gender and religion/beliefs where possible. A group of 4–12 was felt to be optimum to generate discussion while remaining manageable. Separate focus groups for patients and caregivers were conducted so that participants had shared experiences of illness/caregiving and would feel able to speak freely. Inclusion criteria for patients were having an incurable, progressive disease and being an adult (18 years or older). Caregivers were adults with experience of caring for someone with incurable, progressive disease. Participants were recruited via one of the clinicians at the site introducing the study, with follow up by the researcher; via posters displayed in participating sites, which informed potential

participants of the date of the focus group(s) and how to find out more about the study; and/or via letters of invitation sent to potential participants with a study information sheet. We aimed to achieve data saturation, that is, to collect data until analysis resulted in no new themes emerging.³⁵

Data collection

At each site, a researcher with qualitative experience (Appendix 1) conducted two focus groups (one with patients and one with caregivers), following a standardised protocol and training guidelines developed for the study (L.E.S.) based on the literature.^{36,37} The researchers were known to some participants, but were not involved in their care. An observer took field notes. The semi-structured focus groups followed a topic guide developed on the basis of literature and feedback from the project advisory group (Boxes 1 and 2).

Our research was in the subtle realist paradigm, in which reality is conceptualised as existing objectively, but known only from each individual's own perspective.³⁸ This approach, which posits a reality that can be separate from our knowledge of it, is appropriate in qualitative research which aims to accurately describe patient and caregiver experiences and views to inform health service delivery. Data collection was informed by an inclusive definition of spirituality¹ and sought to understand patients' and caregivers' own perspectives. We described the research as focusing on 'those aspects of illness that affect you as a person and might cause you to consider the deeper questions of life'. We defined questions relating to

Box 2. Topic guide for caregiver focus groups.

Preamble: Usually medical care focuses on the physical dimension of health, like controlling pain and other symptoms, but in this discussion, our interest is focused on other aspects of illness and caregiving that affect you and the person you look after and might cause you to consider the deeper questions of life. In this study, we define questions relating to meaning, purpose and how we cope with difficult aspects of life as spiritual questions, but this might not be the word you use. Please use whatever language you want in this discussion.

1. What are the deep questions your loved ones ask themselves these days? *Prompt: would you describe these as spiritual? Does your loved one discuss these concerns with you?*
2. What about you – what are the deep questions you find yourself asking these days?
3. Would you describe any of these deep questions (either your loved one's or yours) as spiritual? If so, why? If not, why not?
4. What do you understand by the word 'spirituality'?
5. What do you understand by 'spiritual care'?
6. Do you think spiritual care should be provided in healthcare? If so, why? If not, why not?
7. In your opinion, what should be the role of different people in providing spiritual support in healthcare? *Discuss each of nurse, doctor, GP, chaplain, social worker, psychologist, volunteer and community faith leaders.*
Prompts: How could these people best support you? Who should initiate discussions of spirituality in healthcare? Why?
8. Based on your own understanding of spirituality, what in your experience are the most helpful things a healthcare provider can do if a caregiver has spiritual concerns? Can you share an example of a caregiving interaction where you felt your spirituality was addressed? *Prompts: If yes, by whom? (Were they from palliative care?) When in your loved one's illness? What happened? What worked well?*
If never experienced, why? (Prompts: staff time/interest, no one asked, did not want to, did not think appropriate to raise, etc.)
9. What are the least helpful things a healthcare professional can do if a caregiver has spiritual concerns? Can you share an example of a caregiving interaction in a clinical setting where your spirituality was not addressed or where you were adversely affected?
10. In your opinion, do you think clinical care for your loved one has addressed his or her spirituality or needs for spiritual support? *Prompts: If yes, by whom? (Were they from palliative care?) When? What happened? What worked well?*
If no, why? (Prompts: staff time/interest, no one asked, did not want to, did not think appropriate to raise, etc.)
11. In your opinion as a caregiver, what are the most important areas of research to improve spiritual care? *Prompts: What do you think would really improve the quality of spiritual care or help better meet your needs?*
12. Is there anything we did not talk about which you think it would be useful to know?

meaning, purpose and how we cope with difficult aspects of life as 'spiritual' questions, but encouraged participants to use whatever language resonated with them.

The data collection documents, information sheets and consent forms were translated from English by the research team at each site where necessary. Focus groups were conducted in the most appropriate language for the location and audio-recorded. Prior to analysis, recordings were transcribed and translated into English by professional translators. The research teams at each site verified the translated transcripts against the recordings.

Analysis

Data were analysed thematically³⁹ in NVivo v10, by qualitative researchers from the United Kingdom, Finland, Canada and New Zealand (L.E.S., L.J.B., S.S., I.K., R.E.). This descriptive methodology was appropriate given the cross-cultural, exploratory nature of the research.⁴⁰ Analysis occurred in stages: after familiarisation with the data, two researchers (L.E.S. and S.S. for patient data; L.E.S. and R.E. for caregiver data) independently developed coding frames based on two focus group transcripts each, generating themes and sub-themes inductively from the data as well as deductively from the topic guide.

Coding frames were compared and integrated to produce two overall coding frames (for patients and for caregivers), including definitions of themes and sub-themes. The coding frames were applied to the remaining transcripts using line-by-line coding (L.E.S., S.S., R.E., L.J.B., I.K.) and findings aggregated in a narrative, paying attention to non-confirmatory cases and differences between patient and caregiver views and experiences (L.E.S.). Field notes were used to contextualise the data and inform interpretation.

Anonymised data extracts are used in presenting findings (Tables 2–4). These are tagged with a unique ID code and location of the focus group.

Ethical approval

Approval to collect data was obtained from all sites' local research ethics committees and for the overall study (Appendix 2). All participants gave written, informed consent.

Results

Participant characteristics

A total of 74 patients and 71 caregivers participated in 22 focus groups ranging 1–2 h (Table 1). Among

Table 1. Participant characteristics.

	Patients (n = 74)	Caregivers (n = 71)	Total (n = 145)
Median age (years), range	62, 28–89	61, 21–92	62, (21–92)
Female, n (%)	48 (64.9)	56 (78.9)	104 (71.7)
Country (n, %)			
Kenya	11 (14.9)	10 (14.1)	21 (14.5)
Korea	9 (12.2)	10 (14.1)	19 (13.1)
UK	8 (10.8)	8 (11.3)	16 (11.0)
Belgium	7 (9.5)	7 (9.9)	14 (9.7)
Poland	7 (9.5)	7 (9.9)	14 (9.7)
South Africa	7 (9.5)	7 (9.9)	14 (9.7)
USA (New York)	7 (9.5)	6 (8.5)	13 (9.0)
Finland	6 (8.1)	5 (7.0)	11 (7.6)
USA (Washington)	5 (6.8)	5 (7.0)	10 (6.9)
USA (San Francisco)	4 (5.4)	3 (4.2)	7 (4.8)
Canada	3 (4.1)	3 (4.2)	6 (4.1)
Religion, n (%)			
Catholic	21 (28.4)	23 (32.4)	44 (30.3)
Protestant	22 (29.7)	21 (29.6)	43 (29.7)
Other Christian	10 (13.6)	6 (8.5)	16 (11.0)
No belief system	1 (1.4)	6 (8.5)	7 (4.8)
Muslim	2 (2.7)	5 (7.0)	7 (4.8)
Buddhist	4 (5.4)	3 (4.2)	7 (4.8)
Atheist/agnostic	2 (2.7)	3 (4.2)	5 (3.4)
Spiritual, not religious	5 (6.8)	1 (1.4)	6 (4.1)
Jewish	2 (2.7)	1 (1.4)	3 (2.1)
Other	3 (4.1)	0	3 (2.1)
Do not wish to disclose	2 (2.7)	0	2 (1.4)
Missing	0	2 (2.8)	2 (1.4)
Fairly/very religious, n (%)	51 (68.9)	48 (67.6)	99 (68.3)
Fairly/very spiritual, n (%)	55 (74.3)	45 (63.4)	100 (69.0)
Patient diagnosis, n (%)			
Cancer	54 (73.0)	52 (73.2)	106 (73.1)
Organ failure	5 (6.8)	8 (11.3)	13 (9.0)
Respiratory disease	5 (6.8)	4 (5.6)	9 (6.2)
Other	6 (8.1)	5 (7.0)	11 (7.6)
HIV	4 (5.4)	0	4 (2.8)
Missing	0	2 (2.8)	2 (1.4)

patients, the median age was 62 years, 48 were women, and 53 had cancer. Caregivers' median age was 61 years and 56 were women. Two-thirds of participants in both groups identified themselves as Christian, with 68% identifying themselves as fairly to very religious and 69% as fairly to very spiritual. Each focus group lasted approximately 90 min.

Findings

Five themes were identified: patients' and caregivers' spiritual concerns, understanding of spirituality and its role in illness, views and experiences of spiritual care, preferences regarding spiritual care, and research priorities. Data saturation was achieved, that is, coding the later transcripts did not result in the identification of new themes in the data.

Patients' and caregivers' spiritual concerns. Patients and caregivers were asked to describe and discuss the 'deeper questions of life' which arose for patients with advanced disease (Table 2). Caregivers were also asked to describe their own deeper questions (Table 3). A wide range of spiritual questions, problems and concerns were reported, arising in four categories: existential, psychological, religious and social/relational. There was striking similarity across sites in the concerns and problems reported, as demonstrated in the data extracts (Tables 2 and 3), although these were framed differently in different contexts; for example, worry about the future for one's family was often compounded by economic concerns in Kenya. Four caregivers (from Poznan, Tampere, London and San Francisco) reported that the patient they cared for did not have, or had not expressed, any 'deeper' questions (Table 4, Q1).

Table 2. Patients' spiritual concerns, as reported by patients and carers.

Category	Question or concern	Exemplifying data extracts
Existential	Asking 'why me?'	I wondered why I was born to have this kind of disease which made my life so much harder. If I have a disease that can be cured, I would not think negatively. Now that I have a bad disease, a flood of thoughts passes through my mind. (SP6, Seoul) My wife has said, 'Why me?' on a number of occasions, how unfair it all is, and she has a brain tumour which is relatively rare I believe. And she finds it very difficult to come to terms with, she [thinks she has] been somehow selected. I am an atheist, and I say no, this is just biological randomness ... 'Why me, why me, why should it happen to me?' It is not easy to explain or comfort. (LC2, London) My belief [is] that God will put a sickness onto you, most of the time, to bring you nearer to Him. (CTP6, Cape Town) It was at the moment when I got to know that I could not be cured, that I looked back on my life and whether I have lived my life well without regret. I wondered myself if I did anything that would harm others or not. (SP4, Seoul)
	Meaning/cause of illness	I was talking to somebody else the other day, and I realised I really didn't have dreams or plans or, you know, to me it has really become a real one day at a time. In that aspect, I don't think I have really gotten a lot of – I mean I have had a lot of positive experiences coming out of this, but that's not one of them, you know. I am just like day to day. I really don't even have dreams of the future anymore. (SFPI, San Francisco) What is the purpose of life, what is the meaning of life? (CTP1, Cape Town) One night by myself I posed the question, 'Do you want to live?' And I realised the answer was 'Yes'. (CP2, Calgary) I think you have to get down to the heart of what makes you worthwhile, where is your worthiness found? And everything that I probably didn't know I found it in had been quite stripped away, so it left my 'self' confused. (CP2, Calgary)
Psychological	Questioning life's purpose or priorities	I have always thought we are born to die, because this is a babe in arms and this is one of the things I think about an awful lot. As time has gone on, I have accepted it a lot better than I did the first year, which I found very hard. (LP5, London) My fears were around just how was I going to cope with what was coming, a tremendous fear about being, uh, was I going to be severely disabled, um, was I going to not be able to drive anymore, um, where was I going to live? (CP2, Calgary)
	General existential questions	I am just finding ways at the moment of, well, not combating but being compassionate towards the fear that comes up when you are on your own at night time, for example. And when the mind is going round and round, you can't sleep. (LP4, London)
	Questioning self-worth	My husband can't talk and it's hard to say what he's thinking ... The look on his face – his eyes. Bulging eyes, full of terror. (PC4, Poznan) [My mother] pretends in front of the doctors that she doesn't need anything, she doesn't say what's bothering her. She doesn't want to say anything, she thinks they have enough things to do ... Sometimes she doesn't ask for help, because she doesn't want to be a burden. She's telling me all the time that if she's too much work, they'll throw her out [of the hospice]. (PC2, Poznan)
	Difficulties with acceptance	They feel like they are a burden and say, 'I see like things are not going on ok; any money that is available goes into buying food; you are not engaging in your usual duties as usual because most of the times you are with me'. (NC9, Nairobi)
	Questioning self-resilience/ability to cope	That helplessness that you feel, the moment you can't do it yourself ... you have to leave everything to others. (LeP5, Leuven)
Religious	Stress, fear	PP7, Poznan: I had a good occupation: I put antenna installations up. Now I'm going to have to let it go. Facilitator: Your whole life you were on the verge of risk? PP7: Yes, always, yes. Facilitator: The disease is a similar situation. PP7: But at work I could belay myself, protect myself to not to get hurt, fall down. Now unfortunately it's not written for me anymore. One shall count on people of good will, but unfortunately there aren't many of them.
	Questioning personal faith	He decided that if this is God's plan for his life, he doesn't want this God. (LC4, London)
	Questioning God	[I ask], 'Why doesn't God put me among all other people who are healthy, why isn't God coming to my rescue in this illness?' (NP1, Nairobi) My husband and I are both from different backgrounds, different religions. And he has never brought up religion before. We are both sort of non-practicing, and he is now in times of, dark times, he is now questioning what God is doing to him. And that's the only time I have heard him talk about religion really. He is now questioning what's happening to him. (LC5, London)
Social and relational	Worry about the future/family	You have no hope; no money; so, you keep asking yourself in your heart, 'What will I do?' You are left asking yourself that question; you respond to it yourself; you ask yourself again and again. (NP6, Nairobi) My daughters were not married, so I was thinking that they should have somebody who would offer them a shoulder to cry on. I was thinking only about them, about my children. (PP3, Poznan) I don't think she is the least bit concerned with what happens to her after she dies. She is very concerned about what happens to me and her family after she dies. (SFC1, San Francisco)
	Relationships, including dealing with stigma and reconciliation with others	My family discriminated against me – my siblings and also including my own mother; I was admitted here in [hospital] for three months and none of them came to visit me. So, I asked myself, 'Why this, God? Do you want to show me that even my family doesn't love me because am sick? If my family has abandoned me, what about those that live around me, how will they perceive me?' (NP8, Nairobi) One of the members [of the patient's Christian church], very prominent in the church, told me that God's given me cancer to punish me because I am too proud. And it was really hitting below the belt you know and it, it really, really hurt and it took me a long, long time to get over it. (LP7, London)

Table 3. Caregivers' spiritual concerns, as reported by caregivers.

Category	Question or concern	Exemplifying data extract
Existential	Questioning 'why them?'	<i>It is the unfairness of it. In fact, I probably deserve all sorts of things going on with me. But he is slim, exercises, never smoked, drinks in moderation ... And this happens to him. (LC8, London, UK)</i> <i>We lived with my mother in law and [I] thought, why he got this kind of disease even though he took care of her and he was such a good man? But I accepted it later. (SC1, Seoul, Korea)</i>
	Questioning 'why me?'	<i>I also ask myself, 'Why was I given this burden?' We were born eight of us and we are all alive, but my sister's burden falls on me since her operation last year ... I ask myself why this has to be me; even when my mother was sick the same thing happened; she also died in my arms. (SC2, Seoul, Korea)</i>
	Looking for meaning	<i>I ask myself this question: what is the meaning of a man's suffering, especially mental ... I grab various answers to this question ... One of the answers that there is, is that suffering ennobles. The other says that suffering toughens us up. Other version I heard says that the road to hell is paved with suffering. So I'm just weighing what's the truth here. (PC5, Poznan, Poland)</i> <i>I am hugely afraid and terribly angry and, uh, very sad. Um, and I don't see a point. I don't see any reason to this except the biological reason, uh, that everybody dies. Um, I absolutely refuse to do the stuff that they call coming to terms with it. (SFC1, San Francisco, USA)</i>
Psychological	Guilt	<i>Even before we went to the doctor, one day when I came to her, she said, 'I'm dying'. And it was terrifying. I just can't imagine it and I feel so guilty that I didn't do anything earlier. (PC2, Poznan, Poland)</i>
	Stress, feeling overwhelmed	<i>When you're taking care of someone, like I say, I'm dealing with my mother and that's almost full-time, it takes away from caring for my husband because he's ill also. But at the end of the day I'm pushing myself, pushing myself, pushing myself, and sometimes it gets overwhelming. I don't know what I'm going to do. I can't, I'm going here and there. (NYC4, New York, USA)</i> <i>I was pretty good the first several months, and as this drags on, I find myself tired, angry and resentful at times and then at other times I just feel completely overwhelmed. And at other times I feel like okay, this is put your head down, this is what we are doing. (SFC2, San Francisco, USA)</i>
	Questioning ability to cope	<i>My question is how am I going to do this, you know. Where do find the strength to do this? As we have said, I am not necessarily, I feel that I am spiritual, but, um, I am not that. I just don't rely on it, and that may be a background of perhaps the science thing has, uh, wormed its way in there and that I am very logical and organised, and, uh, look at the practice stuff more than anything, the hows and the logistics almost of things. (WC3, Washington, DC, USA)</i>
	Worry about the future, including role as carer	<i>How will it end ... How will it go on from here? If things don't go well at a certain moment ... You wonder how it will continue. (LC1, Leuven, Belgium)</i> <i>I just don't want to watch my husband suffer. I don't want prolonged suffering, and we are not spiritually on the same page. And that makes it a difficult ... Because I will be in charge of his care, and I am not sure he would like me to do what I feel is the appropriate thing. I think for me there are moral and ethical dilemmas involved in this ... moral issues, you know. When. What do you do? ... It is like there [are] no answers that anybody is going to be allowed to have except me at the end, and I – that is something that I really need guidance for. (SFC3, San Francisco, USA)</i>
	Difficulties with acceptance	<i>I want to be able to find a place of acceptance, which I am very much struggling with and struggling with trying to accept my husband for the person he has become, because he is not himself anymore. (SFC2, San Francisco, USA)</i>
	Isolation, loneliness of caregiving	<i>So I ask myself, 'God, because you found it fit for us to carry this burden, help us because now I have been left alone; no one wants to get close to us in case we ask them to help us carry our burden'. (NC9, Nairobi, Kenya)</i>
	Feeling insufficient, not knowing what to do	<i>He [patient] just literally was looking at the wall, didn't want to do anything, didn't want to eat or anything. I was struggling. He didn't know what to do. I didn't know what to do. (LC5, London, UK)</i>
	Anger at God/questioning God	<i>I am an Episcopalian, and I can't change the fact that I believe in God and a particular manifestation of God. Um, I am extremely angry with God. I haven't gone to a service, um, in years, um. I definitely feel that God kind of went over the edge on this one ... this is clearly more than people should have to deal with. (SFC1, San Francisco, USA)</i>
Social and relational	Relationships, including change in relationship with the patient	<i>Now that [mother]'s sick, [I am] trying to understand what she's going through, she's not a very talkative person either; if she needs something I have to like think for her or see whether she's got a frown on her face, she's got a pain now, she won't tell me I've got pain, so I have to do the thinking and everything for her. (CTC3, Cape Town, South Africa)</i> <i>Well, I have become a little tougher, but 3 weeks ago, while I returned home from here, I was crying all the way home. I could see all the people who passed away here and who I knew very well. But I can't talk about that to [patient]. I can't talk about it in the evening, I have to let it be, I can't mention it. (LC7, Leuven, Belgium)</i>

Understanding of spirituality and its role in illness. Many patients either described a religious conception of spirituality as related to belief in God (Table 4, Q2) or found the concept difficult to understand or define (Q3 and Q4). Others talked about a deeper dimension of life that was a source of transcendence and meaning, and a coping resource

(Q5–Q7), or described spirituality in relational terms (Q8). Caregivers largely understood spirituality to be a religious concept, but many also stressed that spirituality was distinct from religion (Q9). Relational conceptions of spirituality were common (Q9 and Q10), as well as the view that spirituality means different things to different people (Q11).

Table 4. Exemplifying data extracts, by theme.

1. Patients' and caregivers' spiritual concerns	Q1: No, we didn't have anything like that; we both had a very balanced mind. (TC3, Tampere)
2. Understanding of spirituality and its role in illness	<p>Q2: Spirituality is that our hearts are filled with the Holy Spirit. When we are full of the Holy Spirit, what is it? God comes into our hearts. (SP5, Seoul)</p> <p>Q3: Are spirituality and religion combined or are the two totally separate things? How do you strive for the two? I find it very difficult to sort of put it into a context ... I mean if you ask me am I religious, I mean religious, do you go to church three times a week, whatever? What is spirituality? ... um I grew by sitting outside practically in the garden ... is that spirituality? (CTP2, Cape Town)</p> <p>Q4: This word, 'spiritual', I have never really understood it, what it means. If someone could explain to me, it might help me in the future. I don't know. (LP3, London)</p> <p>Q5: Spirituality gives me the strength to continue living. (NP10, Nairobi)</p> <p>Q6: I have to accept my humanity with its limitations, and this is what spirituality means to me. It lifts me above the things that I can see and feel and touch. (LP2, London)</p> <p>Q7: I believe we are connected to a much greater form and connected to each other. For me, spirituality means being able to feel hope, but not necessarily hope we will be healed but hope for kindness, generosity and freedom from pain. (NYP1, New York)</p> <p>Q8: [Spirituality] is how you react to others, to other people, to other people and close ones and to, to have good relations, whatever it means to everyone, but it is a very broad concept (TP3, Tampere)</p> <p>Q9: I feel too that there was definitely, um, a power and energy out there that we just don't understand at all. Um, and that we can accept or not accept whatever we decide, and, um, for a long time I thought it was really a part of religion because I guess I heard the word first at church and didn't understand it. Um, but I, you know, I have gone beyond that a little bit now. (CC2, Calgary)</p> <p>Q10: It means to me more how you treat people, you know. Not going to church, that's not a spiritual person. You can go to church and be evil. It is more of how you, what you, how you treat people, animals, you know. (CC1, Calgary)</p> <p>Q11: I think when we use this word 'spirituality', it has so many different meanings for different people. For me, it will be everything connected with faith. For somebody else, it would be chanting to music and meditating. (LC4, London)</p> <p>Q12: I think this disease is spiritual because if it was not spiritual, it would be a disease just like any other and I would already have died; this illness is spiritual and its purpose is to facilitate my knowledge of God. (NP1, Nairobi)</p> <p>Q13: I used to ask myself, 'Why should I get sick [when I] am a widow and the one who feeds for my children and all their needs?' And then another spirit tells me, 'There is no one else who would have carried that burden in this home apart from you.' So I continued to pray and God has really helped me. (NP11, Nairobi)</p> <p>Q14: I started to wonder in my head, is it what I have done? ... Because of what the preacher [said] and everything I have been hearing about sin and stuff. I started to believe okay, maybe it is what I have done ... That's why I am in this condition ... What kind of sin would I have committed that would make me have this kind of disease? (LP2, London)</p> <p>Q15: Is it that I have refused to do your [God's] work or I have refused to follow your ways as you would like? (NP3, Nairobi)</p> <p>Q16: I tend to think that lately I may have lots of sins. Therefore, I am not sure about my mind; it just blows hot and cold. When I had a confession, I said to the priest that my sin was that I did not make my children go to the Catholic Church. (SP9, Seoul)</p> <p>Q17: You know when you have a sick person, you have very many questions in your heart; but when God gets into your heart it removes the humanness in that person; when spirituality gets into me, it guides me not to make wrong moves; I get back on my knees and pray and continue with the journey of taking care of my patient; and the fatigue goes. (NC10, Nairobi)</p> <p>Q18: We believe in Buddhism. When we do not feel good, we read 'Cheonsugyeong' [The Thousand Eyes and Hands Sutra] and it made our mind to be calm. (SC1, Seoul)</p> <p>Q19: Spiritual care, the care has a lot to do with praying. Prayer has a lot of good with it because with praying it puts your personal life there ... Prayer is I would say is one of the important things as far as the care is concerned. (CTC5, Cape Town)</p> <p>Q20: To me it is connected with a priest ... I would connect spiritual care to faith, priest, church. (PC2, Poznan)</p> <p>Q21: To help people spiritually to have a good faith as a child of God is spiritual care. Also, it should help them to get blessed. (SP5, Seoul)</p> <p>Q22: ... help somebody overcome any shame they have around talking about life. Their inner journey, their outer journey, the interrelation of all those. (CP2, Calgary)</p> <p>Q23: Spiritual care is a connectedness with someone else, a kind health care provider who is aware of your needs. (NYP4, New York)</p> <p>Q24: When we came here, my husband told me that people here treated him as a human being compared to other hospitals where he was treated as a patient mechanically ... This place is based on spirituality and that makes a difference from other hospitals. We thought that hospice is a place where people are coming to die, but our thoughts have changed while we were here. (SC5, Seoul)</p> <p>Q25: I reckon that spiritual care is creating around the person you're taking care of, a kind of a safety umbrella, building a certainty in this person, that I'm always somewhere there within reach. (PC5, Poznan)</p> <p>Q26: The spiritual side ... I'm not really too concerned about that ... If I'm too much on my own, I do think about it, but that is something different ... to me the first concern is to organise everything: make sure that you're being washed, that there is food on the table, stuff like that, practical stuff. (LeP5, Leuven)</p>
3. Views and experiences of spiritual care (including perceived barriers to its provision)	

(Continued)

Table 4. (Continued)

	<p>Q27: In hospitals or during those times when we meet here or any other place where patients are meeting, spiritual care should be provided. (NP8, Nairobi)</p> <p>Q28: Spiritual care means the whole world, it's more than money, it's more than diamonds ... you cannot weigh it, there's no depth, there's no height, you know, that is what spiritual care is all about. (CTP2, Cape Town)</p> <p>Q29: [Staff] don't have the time to get to the overall thing, instead everyone is taking care of their own little thing. Well, not little, but just their own part ... there should be more [attention to] this overall thing. And spirituality automatically belongs to that. (TP1, Tampere)</p> <p>Q30: My husband wanted to tell about his story to the doctors, but they did not have time to talk; he was dissatisfied with it. It would be great if they listened to patients' stories and what they really want. (SeC3, Seoul)</p> <p>Q31: I need [spiritual care] more than they [the patient] do. They're being taken care of. Everything's being done for them but nobody's helping me. (NYC2, New York)</p> <p>Q32: [The doctor] ended up spending half an hour with me, which in a hospital like this you don't have time for, you know, and she said to me, 'Look, we don't normally ...' and I said, 'No, I know I'm keeping you up.' She said 'No, you need somebody to talk to' and at the same time she could talk to me. It does give you a certain amount of joy, you sort of go out of there afterwards and you forget about little things, little worries that you had on your mind. (CTP3, Cape Town)</p> <p>Q33: CTP1: Compassion doesn't take time.</p> <p>CTP4: They are just the wrong people doing the job for the wrong reason.</p> <p>Patients, Cape Town (discussing poor care received from hospital nurses)</p> <p>Q34: I used to be a nurse myself, and I honestly feel if you want to do it, then you can find the time ... they are just not inclined to. You are there to have your wound dressed or your stitches taken out. Let me get on with that. Your other bits and pieces, I don't really want to know. (LP7, London)</p> <p>Q35: [Staff] should plan their time and say, 'This time we shall deal with spiritual issues and this other time we shall do this and this'. (NP7, Nairobi)</p> <p>Q36: [The consultant] came to sit on her bed and started talking and suddenly it all came out ... It was a big difference from the doctor who had just been there 10 minutes before. Mum didn't tell him anything, but she did to [the consultant], because she had noticed my mother wasn't looking herself. And that makes all the difference. (LeC6, Leuven)</p> <p>Q37: I was on the receiving end of so much I guess what I would consider spiritual care from the ministers at my church. There were also – what do you call it in the hospital? Chaplains, yeh ... I had never been through the death of a loved one before, and they really were there to help me navigate that whole thing. (WC2, Washington, DC)</p> <p>Q38: The nurses ... because they are the closest person that we have contact with. And we see them every day and easily talk with them. (SP4, Seoul)</p> <p>Q39: Although the preacher ... can help me spiritually ... he doesn't know the physical ailment that I have ... For that ailment and my spiritualness to be together ... that's knit with the doctor. (WPP6, Washington)</p> <p>Q40: [The chaplain] ... can reach out to me ... and try to get me to the place where I can get my wholeness together again. (LP7, London)</p> <p>Q41: I think almost anyone, um, anyone who is a caring person can listen, you know, so it can be a nurse, it can be a doctor, can be ... Someone who is taking you for a drive. (CC2, Calgary)</p> <p>Q42: There are those who do the work, and then there are those who personally take care of you. There is a difference. That is the most important to me. (LeP6, Leuven)</p> <p>Q43: It definitely mustn't come from a religious angle, it mustn't be like Roman Catholic or Islamic or whatever. (CTP4, Cape Town)</p> <p>Q44: You need somebody ... to say to you 'Now, stop and listen and let's talk it through. I am not going to judge. I am not going to condemn you. Tell me how you feel and we will take it from there' ... And from there you can both walk together. (LP7, London)</p> <p>Q45: A religious affiliated hospital can, on the one hand, be more 'pro' providing spiritual care, and on the other hand, they can also be more likely to assume that everybody has got what their faith tradition is. Someone walked in and the first spiritual care question was 'Would you like prayer?' That's already making a big assumption about the patient in the bed. (WC2, Washington, DC)</p> <p>Q46: The most important, to me, is trust. It is good to have someone in front of you who you can trust, and to who you can talk about your concerns, that is what you need. I'm not sure if there is one general solution for that, because everyone is different. I don't think you can just learn from a book. That is knowledge, and feeling the needs of a person, like, he needs this, he needs that, that is him ... everyone is different. You can't just find one solution for that. (LeP5, Leuven)</p> <p>Q47: Create a metal detector for empathy ... And you will probably have the most successful spiritual care department that ever existed. (CP2, Calgary)</p> <p>Q48: How is it communicated to the patient? What are the words? What is the semantics? What is the invitation? Because the department exists but how, um, it is all how you pitch it. How is it marketed to the patient? And does that affect whether the patient signs up or not, um, for spiritual care? (CP1, Calgary)</p> <p>Q49: You can learn things. How to make things negotiable. Sensitivity or tact is something you have or not. But you can show the different possibilities, just like [participant] said, you can tell nurses what to do, at least they know then, and then they can choose whether or not they want to do it. But if they don't know ... there must be some techniques for that. (LeC5, Leuven)</p> <p>Q50: When somebody says no, I don't have any religion ... maybe the checklist could have a spirituality [question]? Okay, would you like somebody else to talk to? And maybe it is somebody who comes in maybe in a collar or when he comes in there, he takes the collar off. And just somebody comes in and says okay, is there something you want to talk about? ... There may be a way of helping people in the future that don't have a faith. (LC9, London)</p>
4. Preferences regarding spiritual care: which staff members should provide it, and how?	
5. Research priorities	

For some patients, illness was inherently spiritual (Q12). Some patients drew upon their spiritual beliefs and were supported by spiritual leaders and faith communities to help them cope with and accept their illness (Q13). Conversely, framing their illness in relation to their beliefs led other patients to blame themselves or their imperfect past behaviour for their current situation (Q14–Q16). Caregivers described how their beliefs, spiritual practices (e.g. meditation, prayer) and support from their faith community helped them cope with their role (Q17 and Q18).

Views and experiences of spiritual care, including perceived barriers. Just as participants' conceptions of spirituality varied, so did their understandings of spiritual care. Some participants understood it to be essentially religious; for example, in Cape Town and Nairobi, caregivers talked about spiritual care as prayer, while in Poland, caregivers related spiritual care to seeing a priest (Q19 and Q20). Some religious patients saw the primary purpose of spiritual care to be helping them integrate their personal faith into the illness experience (Q21). However, many participants across the sites did not consider spiritual care to be religious care, instead describing it as providing a safe space, listening and counselling. These patients emphasised the role of spiritual care in providing existential support and human connection at a difficult time (Q22 and Q23). Some caregivers understood spiritual care broadly to encompass all care that goes beyond consideration of physical needs. In this sense, they saw palliative care staff as providing spiritual care and their own caregiving as essentially spiritual (Q24 and Q25).

There was some variation across sites regarding the importance patients and caregivers placed on spiritual care; for example, patients and caregivers in Belgium were less likely to see it as a fundamental component of healthcare compared to those in Africa (Q26 and Q27). However, most patients and caregivers across sites agreed that spiritual care was an essential facet of whole person care that should be addressed in healthcare when approaching the end of life (Q28).

Both patients and caregivers reported that spiritual care for patients was lacking (Q29 and Q30). Inadequate spiritual support for caregivers was also noted (Q31). Participants perceived insufficient staff time (Q32) as a barrier to the provision of good spiritual care. However, others suggested that its neglect might have more to do with lack of motivation, prioritisation and/or interest on the parts of healthcare providers (Q33–Q35). Participants generally reported good experiences of spiritual care when received (Q36 and Q37).

Preferences regarding spiritual care: which staff members should provide it, and how? Patients' preferences regarding who provides spiritual care varied widely and included doctors, nurses and healthcare assistants, as well as trained spiritual care specialists. Nurses and healthcare assistants were preferred by many, as patients tended to have most contact and familiarity with them (Q38). Physicians were

identified as essential in providing spiritual care, due to their relationship with patients and their important role in treating the patient's illness (Q39). The role of spiritual care specialists was also recognised and valued (Q40). Caregivers emphasised that spiritual care was a responsibility of all staff and appreciated volunteers and peer support (Q41).

Human connection was perceived as a prerequisite to providing effective spiritual care. Patients and caregivers described essential approaches to care that engendered this human connection: putting the patient first, making an extra effort, being reliable and present, and seeing spiritual care as an integral part of care. Additionally, patients felt there were intrapersonal factors or attitudes that predicated a human connection: openness, respect, genuineness, non-judgement, hopefulness, honesty, empathy, kindness and being spiritually aware (Q42–44). Proselytisation and other prescriptive approaches to spiritual care were highlighted as insensitive and inappropriate (Q45). Participants emphasised that spiritual care needed to be individualised and that staff should avoid categorising or stereotyping (Q46).

Research priorities. When asked to consider spiritual care research priorities, patients identified a need to understand the qualities, nature and practice of human connectedness (e.g. compassion, empathy) (Q47). Patients' other priorities included communicating sensitively about spirituality, particularly in initiating conversations about spiritual care needs (Q48); raising patient awareness of the availability of spiritual care and self-care practices; improving public discussion of death and dying; and how to provide spiritual care within the time constraints of contemporary healthcare. Research that was multi-professional and informed by patients was recommended.

Caregivers emphasised the need to develop educational interventions for staff (Q49); investigate ways to make spiritual care suitable for diverse populations, including those of no religious faith (Q50); improve the assessment of spiritual care needs; study the impact of spiritual care and consider carers' spiritual care needs, including during bereavement.

Discussion

Main findings

This study provides, for the first time, a picture of patients' and caregivers' spiritual concerns, spiritual care experiences and preferences, and priorities in spiritual care research in an international sample. Participants described a wide range of 'deeper' concerns that were remarkably common across countries. These concerns were spiritual in the sense of relating to ultimate meaning, purpose, transcendence and relationships to self, others and the significant/sacred.¹ Many concerns were existential, psychological and social/relational in nature rather than overtly religious, although religious distress (related to the

content of beliefs and questioning one's faith) was also evident.

The rich descriptions of spiritual concerns in this study highlight the importance of attending to these in palliative care. However, participants reported a wide-spread neglect of spiritual care needs in practice: spiritual care was needed and felt to be important, but was frequently not addressed by healthcare providers. Participants suggested that the neglect of spiritual care was a matter of prioritisation and staff attitude as much as lack of time. Participants had wide-ranging preferences regarding who provides spiritual care, valuing both specialist and non-specialist spiritual care providers. This suggests that the most appropriate person to provide spiritual support depends on the individual patient or caregiver, as well as the type and severity of distress and the skills of the healthcare professional. Across sites, there were commonalities in the attitudes and approaches perceived as necessary to spiritual care, regardless of who provided it.

Patients emphasised the need for patient-informed multi-disciplinary research into the innate and relational qualities of spiritual care and how to foster them among staff. Their other priorities included communicating sensitively, raising patient awareness of spiritual care and self-care practices, improving public discussion of death and dying and how to provide spiritual care given time limitations. Caregivers highlighted the need to develop educational interventions for staff, make spiritual care suitable for diverse populations, improve assessment, study the impact of spiritual care and consider caregivers' spiritual care needs, including during bereavement.

Strengths and weaknesses of the study

A strength of the study is that it was informed by an inclusive conceptualisation of spirituality, and participants were encouraged to speak about their deepest concerns and needs in their own language. There is much debate about definitions of spirituality, and adopting an inclusive definition means we captured social and psychological concerns as well as those narrowly conceived of as 'spiritual'. We believe this reflects the complexity of human experience, which is not easily compartmentalised into 'spiritual', 'social' and 'psychological', and in which relationships are key.⁴¹ Recruiting from nine countries provides an overall picture of patients' and caregivers' views, experiences, preferences and priorities internationally, and we achieved data saturation. However, the study was not designed to explore differences in experiences by site or within each country: just two focus groups were conducted at each site, and we did not aim for data saturation at each site. Data should not be taken as representative of the views and experiences of patients and caregivers in that country and cannot result in site- or country-specific recommendations for improving spiritual care. Findings should also not be extrapolated beyond the nine countries involved, as patients

and caregivers in other countries might have different experiences and views. A limitation of this study is that we did not have the resources to conduct back translation to check the validity of the translations. However, the local researchers at the sites (who were fluent in English as well as the local language) checked the transcripts for accuracy. Despite our intention to recruit a diverse sample, most participants had cancer and identified as at least fairly religious and Christian, although, as the data extracts show, there was a continuum of secular and religious views. These factors could limit the transferability of findings.

What this study adds

Our findings contribute to the understanding of patients' and caregivers' spiritual care needs, preferences and experiences towards the end of life provided by qualitative studies from New Zealand,³ Australia,⁴² Norway,⁴³ the United Kingdom,⁴⁴ the United States,^{45,46} Taiwan,^{47,48} Japan⁴⁹ and India.⁵⁰ We found that patients and caregivers experience a range of existential, psychological, religious and social concerns; these reflect both the existential concerns (e.g. threats to self-identity) emphasised in Henoch and Danielson's review⁵¹ and the relational concerns that emerged as central in Edwards et al's⁴¹ review of qualitative literature on understandings of spirituality.

The finding that spiritual care is needed but neglected supports other evidence of a lack of attention to spiritual care needs.^{2,5,13–20} Participants' view that lack of time was not the main reason for this neglect echoes Balboni et al.'s study, which found that neither lack of time nor space was associated with spiritual care provision in oncology. Rather, the barriers were inadequate training, clinicians not viewing it as their professional role, and worry that spiritual care is inappropriate due to power inequity between patient and clinician.⁵² Other studies have identified additional barriers: lack of expertise and the sense that others could do a better job.⁵³ Among nurses, higher perceived competence in spiritual care is associated with viewing spirituality/spiritual care broadly, not just in religious terms.^{54,55} Taken together, these studies suggest specific areas of education to improve spiritual care; for example, deepening practitioner's self-awareness and self-understanding to help promote human connectedness, and ensuring that spiritual care is understood not purely as religious care. However, changes to organisational culture are also needed to shift practice,^{56,57} for example, incentivising good spiritual care provision via quality indicators and paying staff for time spent on spiritual care. Our findings support models of palliative care which emphasise that all staff should be comfortable with, and competent to provide, a basic level of spiritual care, with more advanced psycho-spiritual and religious support provided by specialists.^{58,59} The virtues of openness, authenticity, non-judgement and kindness which patients described have been identified as essential

motivators in compassionate care⁶⁰ and appear in a conceptual analysis of spiritual care in nursing.⁶¹

Researchers and clinicians in the EAPC survey³⁴ prioritised research into spiritual care interventions and their effectiveness, overcoming barriers in spiritual care due to staff attitudes, helping staff talk about spiritual issues (e.g. via conversation models), screening and assessment and understanding needs and preferences in multi-faith, multi-cultural populations. These priorities overlap with patients' prioritisation of communication and how to provide spiritual care, and caregiver's prioritisation of assessment and impact. However, patients were more focused on understanding the qualities or attributes of spiritual care providers than caregivers and survey respondents. This echoes findings from other studies^{62–65} and suggests that for patients, the quality of spiritual care depends on the quality of human connection rather than the nature of the intervention itself. Clinicians' and researchers' prioritisation of spiritual care interventions rather than attitudes might reflect a professional emphasis on 'doing', rather than the 'being'⁶⁶ often emphasised in spiritual care practice.⁶⁵

We found that while individuals are unique in expressions of spirituality, there are commonalities that can serve as pillars for ongoing international collaboration to improve spiritual care (e.g. The Global Network for Spirituality & Health⁶⁷). Findings suggest that training staff and volunteers in spiritual care provision in palliative care must become an international priority. They also provide a framework for future research, providing the service user counterpart to the research priorities previously identified.³⁴ Further research is needed to explore cultural differences in service users' experiences and preferences and identify models of spiritual care that are culturally sensitive and locally appropriate.

Conclusion

Our findings provide evidence that spiritual care is an essential but neglected component of care, according to patients and their caregivers across a range of countries. Participants described human connection, person-centredness and integration in healthcare as fundamental to spiritual care. While spiritual care specialists play important roles, including staff support, participants emphasised the importance of spiritual care competency across disciplines. The priorities identified here should be used to guide future spiritual care research and clinical and educational initiatives.

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Data sharing

Requests to access anonymised transcripts should be directed to the corresponding author (L.S.).

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Ethics and consent

This study was approved by the ethical review boards of the participating sites (Appendix 2). All participants provided written informed consent.

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Appendix 1. FG facilitator characteristics.

Site	Occupation	Gender	Highest qualification
Calgary	Chaplain and researcher	M	PhD
United Kingdom	Chaplain and researcher	M	PhD
Washington, DC	Physician and researcher	F	MD
Poznan	Psychologist and lecturer	F	MSc
Cape Town	Researcher	F	BA, PGDip Pall Med
San Francisco	Researcher	F	PhD
Tampere	Researcher	M	PhD
Nairobi	Researcher	F	BA
Seoul	Nun and researcher	F	PhD
Belgium	General practitioner and researcher	F	PhD
New York	Chaplain and researcher	M	BCC

Appendix 2. Ethical approvals received.

Organisation	Reference	Date
King's College London Biomedical Sciences, Dentistry, Medicine Research Ethics Committee	BDM/12/13-124	14 August 2013
Ethics Committee of Pirkanmaa Hospital District, Tampere	R13158H	19 February 2014
IRB of Songeui Medical Campus, The Catholic University of Korea	MC13QISI0090	24 December 2013
Conjoint Research Ethics Board, University of Calgary	REB13-0764	13 January 2013
Nairobi Hospice Standards and Ethics Committee	N/A	6 January 2013
Beth Israel Medical Center Institutional Review Board	#152-13	30 October 2013
University of California, San Francisco, Committee on Human Research	14-13072, 081952	21 April 2014
University of Cape Town Human Research Ethics Committee	670/2013	9 December 2013
The George Washington University Committee on Human Research IRB	FWA00005945	12 February 2014
Poznan University of Medical Sciences Ethics Committee	724/14	4 September 2014
Medical Ethics Committee KU Leuven	S55823	21 March 2014